Original Article

Dominant Factors Affecting Maternal Resilience Scores in Children with Down Syndrome

Aries Abiyoga[1*,2], Zamzaliza Bt Abdul Mulud[1]

ABSTRACT

OBJECTIVE: To determine the Leading Factors Affecting Maternal Resilience Scores in Children with Down Syndrome

METHODOLOGY: A cross-sectional study was conducted between February and April 2024 at the Association of Parents of Children with Down's Syndrome in East Kalimantan, Indonesia. The sample size was determined based on a total population of 209 POTADS. Using Rao-soft calculations with a margin of error of 5% and a confidence level of 95%, 135 respondents were recommended as the sample size. The Par-DD-QoL questionnaire, which consists of 18 items overall, was modified from the Par ENT survey to assess parents' quality of life. The respondents were selected using nonpurposive sampling. Microsoft Excel entered the collected data, and SPSS 26 was used for analysis.

RESULTS: The study found that social support, caregiver burden, and quality of life significantly affected maternal resilience in parents of children with Down syndrome. Those with higher quality of life and social support were more likely to have higher resilience levels. These findings emphasize the importance of addressing physical and psychological well-being to promote resilience in this population. Thus, addressing both physical and mental well-being is essential for fostering resilience in children with Down syndrome.

CONCLUSION: Providing support and resources for parents and caregivers is crucial for resilience in children with Down syndrome. A holistic approach that considers an individual's quality of life and the social support system is critical to enhancing resilience, which comes with the job by concentrating on these factors.

KEYWORDS: Down Syndrome, Quality of Life, Caregiver Burden, Community Assistance, Resilience

INTRODUCTION

Down syndrome is the most common genetic disorder and the easiest to detect. Because there is an extra chromosome on chromosome 21, Down syndrome is more commonly known as a trisomy genetic disease[1,2]. Patients usually have growth retardation, distinctive facial traits, and mild to moderate intellectual difficulties when they first arrive. Extra chromosomes result in an overabundance of particular proteins that disrupt the body's normal growth and alter previously organized brain development[3].

It is a significant and fascinating research topic because of the quality of life experienced by parents of children with disabilities. Refers to the parent's condition, who is the closest person to thechild, it is directly affected by the pressures of education and the child's unique needs[4,5]. The child's initial physical and psychological experience must be passed on to his mother and father. It is essential to understand the quality of life experienced by parents of children with special needs because of the unique role and function that these parents play in the development of their children [6]. Parents with ASD have lower life quality and social functioning values than families with children with other types of disabilities[7]. owing to the increased parental stress caused by the numerous challenges faced in caring for children with ASD, such as behavioral issues, emotional control, social problems, anxiety, and depression. Parents' physical and emotional health affects their capacity and ability tocare for their children. When parents' quality of life declines, their ability to care for their children also deteriorates[8].

Social assistance aids in the process of adjusting to unfavourable circumstances. Seldom do families who have a strong sense of social support feel lonely[9]. Families with high levels of perceived social support had favorable psychosocial profiles. In addition, an individual's perception of low social support may have an unfavorable impact. A common perception of social support can make individuals feel lonely, and this low perception harms their quality of life[10]. Depressive symptoms can increase without an individual's perception of social support[11]. Seeking out and maintaining positive relationships can help mitigate the negative effects of low social support on mental health[12].

Parents who have children with Down syndrome need

[1]Centre for Nursing Studies, Faculty of Health Sciences, Universiti Teknologi MARA, Puncak Alam Campus, Selangor, Malaysia
[2]Department of Nursing, Institute of Health Technology and Science Wiyata Husada Samarinda, Indonesia
Correspondence: *ariesabiyoga90@gmail.com*
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to make significant adjustments to overcome the difficulties they experience to re-establish proper functioning. Children with Down syndrome have the right to be treated equally and have the same opportunities in all aspects of their lives[13] By empowering parents to be enthusiastic about helping their unique children grow and develop optimally; they can become independent and become individuals with wider community can accept. Good resilience is characterized by empathy, composure, optimism, and a belief that things can improve. People have control over their lives and have hope for the future. Being optimistic improves one's physical health and lowers the likelihood of developing depression[14]. The ability to mentally overcome adversity and carry on with a functioning, healthy life is known as resilience. Thus, resilience can be simplified as finding the positive side behind difficulties and using it as a strength to rise; this shows that some parents do not understand the function of resilience[15]. Carefully planned research is required to investigate the critical variables of resilience, quality of life, social support, and carer burden in parents of children with Down syndrome.

The study aimed to determine the Leading Factors Impacting Parents of Down Syndrome Children's Maternal Resilience Scores. The study's novelty is identifying specific factors that can help support parents in their caregiving role and improve their overall well-being. This research offers insightful information to create focused interventions to assist parents of children with Down syndrome.

METHODOLOGY

This Cross-sectional study was conducted between February and April 2024. One hundred thirty-five children with the Association of Parents of Down Syndrome Children (POTADS) participated. The population of this study is parents who are members of the Association of Parents with Down Syndrome Children in East Kalimantan province spread over districts seven/cities, such as Samarinda with 209 children, East Kutai with 19 children, North Penajam Paser with four children, Bontang with 14 children, Balikpapan with 31 children, Kutai Kartanegara with 22 children, and Berau with 3 children.

The sample size was calculated based on a total population of 209 POTADS members. Using Raosoft calculations with a margin of error of 5% confidence level of 95%, 135 respondents were recommended as the sample size. The respondents were selected using nonpurposive sampling. The researcher personally approached the respondents for an agreed-upon time contract. The questionnaire was administered after the respondent agreed to participate and signed the consent form. All respondents were informed that all data would be kept confidential. The inclusion criteria were mothers who had children with Down Syndrome, lived together and were eligible to participate in this study, for the exclusion criteria, and mothers who cannot communicate or have cognitive problems.

To measure the variables in this study, researchers used a set of questionnaires in Indonesian and English to determine the research objectives. This instrument consists of two parts: part one for socio-demographics (age, education level, employment and income) and part two for each variable (quality of life, Caregiver Burden, Social Support and Resilience). The Parental-Developmental Disorder-Quality of Life (Par-DD-QoL) questionnaire, which consists of 18 items overall, was modified from the Par ENT survey to assess parent's quality of life. This questionnaire was translated into Indonesian by a previous researcher, Titis Nur Latifah, and has beentested for validity and reliability, with a Cronbach's reliability value of 0.903 and validityof 0.223 -0.692. A scale of ≥66 for high quality of life, 42–65 for moderate quality of life, and <42 for low quality of life is used to evaluate life satisfaction. This scale has good consistency or reliability, with a Cronbach's alpha value between 0.903 and a validity level of 0.223-0.692.

The researchers asked 22 questions regarding the burden (caregiver burden) on caregivers as parents of children with Down syndrome. Questions in the questionnaire focused on the physical health of the caregiver (four questions), the psychological health of the caregiver (seven questions), the economy (three questions), social life (three questions), and the relationship between the caregiver and the sufferer (five questions). This questionnaire uses a numerical or interval scale. Data on parental burden (caregiver burden) were obtained using a Likert scale. In this questionnaire, there were four answer choices in the form of closed-ended questions: 0 = never, 1 = rarely, 2 = sometimes, 3 = very often, and 4 = almost always. This questionnaire's measurement data were split into four sections: 0–20 no or little load, 21–40 light to moderate load, 41–60 moderate to heavy load, and 61 –88 heavy load. In this face validity test, researchers received expert guidance during the guidance process. In the guidance process, experts added and improved the sentence structure of each question in the questionnaire so that it was easy for respondents to understand. The reliability test results of the caregiver burden questionnaire were reliable, with a Cronbach's alpha (0.804).

Social support was measured using a questionnaire compiled by researchers based on Cutrona et al. 's theory of the types of social support (Sarafino & Timothy, 2011). The researchers then asked 27 questions. After calculating each research variable's hypothetical and empirical scores, we categorized the participants on three norm levels: low < 54, medium < 81, and high > 81. The questionnaire was reliable, with a Cronbach's alpha (0.911).

The Resilience Scale has 23 items that use six alternative answers. The alternative answers were very unsuitable, inappropriate, somewhat unsuitable, appropriate, appropriate, and very appropriate. The level of resilience was assessed by a range of scores: > 138, very high resistance; 123-138, high resistance;

108-123, medium resistance; 93-108, low resistance; and < 93, very low resistance based on hypothetical and empirical categorization. This scale has good consistency and reliability, with a Cronbach's alpha value between 0.932 and a validity level of 0.302-0.770[16].

The instrument used in this study was a questionnaire. A permission letter outlining the study's features, advantages, confidentiality, anonymity assurances, and the opportunity to end the study at any time without facing repercussions from the institution for the patient or participant was also provided to the participants. Instructions for completing the socio-demographic data questionnaire were sent only to parents who consented to participate.

IBM SPSS Statistics version 26 was utilized to analyze the collected data, which was then input into Microsoft Excel. The socio-demographic prevalence was ascertained using descriptive statistical analysis, and the resilience predictors were ascertained using a basic linear regression model. The results are shown as the correlation coefficient (R), mean and standard deviation, frequency (n), and percentage (%). P < 0.05 was used in every test to indicate the significance threshold.

RESULTS

Demographics and variables of participants

Table I shows the results of the Demographic Variables of 135 participants, with the majority age being 26–35 years (n = 55, 40.7%). The educational background of the majority of respondents was high school; 74 (54.8%) and 88 (65.2%) did not work. Most respondents had an income of > 1,000,001–3,000,000, 85 (63.0%). The data indicates that a significant portion of the participants were relatively young adults with a high school education and a moderate income level.

TABLE I: DATA DEMOGRAPHIC

Socio-demographic	Response	Result	
		n(%)	Mean±SD
Mother's age	17-25	25 (18,5%)	31,67±8,94
	26-35	55 (40,7%)	
	36-45	41 (30,4%)	
	46-55	14 (10,4%)	
Education	Elementary School	4 (3,0%)	
	Junior High School	13 (9,6%)	
	Senior High School	74 (54,8%)	
	College/University	44 (32,6%)	
Employment Status	Not Working/Housewife	88 (65,2%)	
	Private	41 (30,4%)	
	Government Officials	6 (4,4%)	
Household Income/month (Rp)	< 1.000.000	38 (27,4%)	
	>1.000.001–3.000.000	85 (63,0%)	
	> 3.000.001	13 (10,4%)	

Table II shows the association between the socio-demographic information and the mother's quality of life as inferred from inferential statistical data. A correlation was seen between the QoL scores and age (p = 0.004). Age and the caregiver burden index were significantly correlated (p=0.006). Maternal education and resilience scores were positively correlated statistically (p = 0.020).

TABLE II: RELATIONSHIPS BETWEEN SOCIAL DEMOGRAPHIC INFORMATION AND RESILIENCE, CARER BURDEN, QUALITY OF LIFE, AND SOCIAL SUPPORT

Variables	P-Value
Relationship between quality of life and socio-demographic information	
Age	0,004
Education	0.070
Employment Status	0.174
Household Income/month (Rp)	0.476
Association between Socio-demographic Data with Caregiver Burden	
Age	0.006
Education	0.261
Employment Status	0.633
Household Income/month (Rp)	0.595
Association between Socio-demographic data with Social Support	
Age	0,768
Education	0.752
Employment Status	0.972
Household Income/month (Rp)	0,922
Association between Socio-demographic data with resilience	
Age	0,472
Education	0.020
Employment Status	0.174
Household Income/month (Rp)	0.342

A non-parametric test analysis using Spearman's correlation examined the association between maternal resilience and quality of life, carer burden, and social support.

Table III illustrates the correlation between resilience and quality of life among parents of children with Down syndrome. The results showed a significant positive correlation between maternal resilience and quality of life (R = -0.366, p < 0.00); this suggests that higher levels of maternal resilience are associated with better quality of life outcomes for parents of children with Down syndrome.

Table IV presents the outcomes of multiple linear regression; quality of life and social support

significantly impacted the resilience score (F = 17.483, $p < 0.001$). In addition, R = 0.458 and R^2= 0.197 illustrate that the model explains 19.7 % of the variance in the resilience scores. In addition, the coefficients were assessed to ascertain the influence of QOL on the maternal resilience variables. The results showed that the dominant factor was the quality of life variable, significantly negatively impacting maternal resilience scores (B = -0.444, t = -5.646, p = 0.000). Based on a simultaneous test using the F-test statistic, where H0 is (the predictor variable simultaneously does not influence the response variable Y) and the alternative hypothesis (H1) is (the predictor variable simultaneously influences the response variable Y), There was a 0.000 p-value less than the value of 0.05. Therefore, it may be said that the predictor variables simultaneously influence the response variable Y.

TABLE III: ASSOCIATION BETWEEN QUALITY OF LIFE, CAREGIVER BURDEN, SOCIAL SUPPORT WITH RESILIENCE AMONG PARENTS WITH DOWN SYNDROME CHILDREN

Variable	Score Resilience	
	R	P-Value
Score Quality of Life	- 0.336**	0.000
Score Caregiver Burden	- 0.088**	0.311
Score Social Support	- 0.158	0.068

Spearman's Correlation

TABLE IV: COEFFICIENT OF DETERMINATION

Model	R	R²	p-Value
Quality of Life	0.458	0.197	0.000*
Social Support			0.007*
Caregiver Burden			0.472

DISCUSSION

The study found a significant correlation between socio-demographic data, maternal quality of life, caregiver burden, and maternal education. Higher education levels were linked to lower caregiver burden and improved quality of life. The findings suggest the importance of social support in reducing caregiver stress. Without a doubt, given that Down syndrome is a lifelong disorder and that carer responsibilities increase as people with Down syndrome age, parents of children with the disorder are more likely to experience high levels of stress in terms of their quality of life, social support, and caregiving burden [17,18]. However, a person's quality of life, social support, and caregiving responsibilities increase over time, and certain personality traits and abilities become crucial for adjusting to new circumstances [19]. These parents often exhibit resilience, patience, and empathy as they navigate the challenges of caring for a child with Down Syndrome. Through their experiences, they may also develop a strong sense of community and support networks that help them cope with caregiving demands. A more profound comprehension of the unique requirements and skills of people with Down syndrome can result from this and a stronger sense of fulfilment and purpose in their job as carers. Parents and other carers may find caring for a person with Down syndrome to be fulfilling and life-changing, despite the challenges involved[20,21].

The correlation coefficient was statistically significant, indicating a moderately positive relationship between QoL and resilience. Parents of children with Down syndrome who have a higher quality of life may be more resilient as mothers; this can happen because a better quality of life can provide the emotional and mental support needed to face the challenges of caring for children with Down syndrome. Therefore, parents must maintain their quality of life to strengthen their resilience in difficult situations. Quality of life is always linked to the strength of children with Down syndrome; therefore, maintaining a balance between the two can help parents face daily challenges. With social support and good self-care, parents can improve their quality of life and resilience when caring for children with Down syndrome.

According to descriptive analysis, the participants' quality of life, social support, and caregiving burden were moderate. When examining mediation analysis, statistical analysis revealed a negative relationship between three resilience measures and quality of life, social support, and carer load. Quality of life significantly mediates the association between self-resilience, hope, and well-being. However, the relationship between optimism and well-being is not mediated by quality of life [22,23]. The total impact is positive and significant, and quality of life is an essential mediator in the relationship between parental resilience and caring for children with Down Syndrome [24–26].

The obligations placed on families, social support networks, and family demographics all seem to have a significant impact on how families react to the birth of a child with Down syndrome [27]. If practitioners who work with families of children with Down syndrome are aware of the elements that support normal family functioning, treatment for these children and their families may be more successful [28,29]. Social support is one factor that plays a role in shaping someone into a firm or resilient person[3]. It shows that the higher the social support a person receives, the higher their resilience. By receiving social support from an association of parents with children with similar conditions, parents feel loved, valuable, and appreciated[31].

The extra strain of daily tasks placed on parents of children with Down syndrome (DS) can hurt their health. There are numerous obstacles in the daily lives of parents who are the children with disabilities' primary carers. In line with research by Mishra TA 2023[32], it was concluded that mothers who have

children with Down syndrome tend to have a high level of caregiving burden, and this is related to age at birth. Therefore, health service providers, including relevant authorities, are advised to carry out various programs to support nurses in reducing their burden and increasing awareness regarding Down syndrome prevention measures in the community[33].

By adjusting to one's talents and efficiently using external elements, resilience helps people adapt to life's challenges precisely, consistently, and persistently. The ability to deal well with challenges, setbacks, unpleasant experiences, and growing responsibilities indicates positive adaptation[34]. Therefore, resilience is the capacity of an individual to bear unfavourable experiences and revert to a baseline level of equilibrium and functioning. High resilience individuals exhibit traits that enhance their well-being and quality of life, such as independence, self-assurance, humour, patience, positive emotions, openness to new experiences, and determination in action[35].

The study emphasizes the importance of screening for maternal resilience, as early intervention can improve mothers' quality of life and socialization. It also highlights the significant impact of workload on resilience, with 88 mothers not working compared to 47. Future research should focus on strengthening resilience in older adults.

CONCLUSION

Social support, caregiving burden, and quality of life are the main variables that influence maternal resilience scores among parents of children with Down syndrome. Resilience tends to be higher in those with better lives and more supportive social networks. The findings suggest that a person's resilience is primarily determined by their quality of life and social support. In addition, education is also a supporting factor that influences maternal resilience scores. Improving quality of life could potentially lead to higher levels of resilience in mothers. Maternal resilience and quality of life were significantly correlated, suggesting that treatments targeted at improving quality of life could benefit mothers' resilience. These results emphasize how critical it is to treat mental and physical health issues to support resilience in this population.

Future research should explore other factors contributing to resilience, such as coping strategies and personality traits. Therefore, nursing service providers can consider nursing care using this method for early detection in maintaining the strength of parents of children with Down Syndrome.

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AUTHOR CONTRIBUTION

Abiyoga A: Design methodology and supervised the findings of this study, Conceptualization, Data Analysis, and Interpretation.

Mulud ZBA: Conceptual Framework and Data Analysis

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